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PRACTICE

ESSENTIALS

Supporting relatives and carers at the end of a patient's life

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“How people die remains in the memory of those who live on” — Cicely Saunders

All doctors, irrespective of their specialty or the setting in which they work, will care for patients who die. Around half of all deaths occur in hospitals.¹ Evidence suggests that the quality of communication around this process is poorer in hospitals than in other settings, according to responses from relatives who have experienced bereavement.² Over half of NHS complaints concern care of the dying.³

This article discusses how to best support relatives and carers at the end of a patient's life. While the focus is on the hospital setting, the principles are applicable to community and care home settings. In this article, “relative” encompasses family members, care givers, and those close to the patient. The article presumes throughout that the patient has given consent for information to be shared with relatives (Box 1).

Communicate and anticipate individual needs

Grief is a normal human reaction to loss, however the manner in which professionals respond to those facing bereavement can have a long term impact on how they grieve, and on their health. For example, support from specialist palliative care teams can lead to improved short and long term outcomes for the bereaved.⁶ In contrast, a poor relationship between healthcare providers and families, and poor communication, are risk factors for adverse bereavement outcomes such as complex grief, experienced by about 20% of bereaved relatives (Box 2).⁷

Good verbal communication with relatives facing bereavement encompasses both practical and emotional support. Written communication, for example information leaflets, can also be helpful.^{9 10}

Sensitively discuss with relatives the deteriorating clinical condition of the patient, and whether there are any potential

reversible causes. Consider with relatives whether clinical interventions such as antibiotics, nutrition and hydration, patient monitoring, blood tests, and intravenous lines are appropriate. It is good practice to discuss cardiopulmonary resuscitation, even if previously discussed with the patient so that relatives have a chance to express their views. Explain to relatives that a Do Not Attempt Cardiopulmonary Resuscitation order does not imply that no care will be given; rather all care deemed clinically appropriate will be given except cardiopulmonary resuscitation. Create an individualised multidisciplinary care plan for all patients whose deaths are expected.¹¹ Talk this through with relatives.

Relatives need to balance visiting the patient with other responsibilities, such as work and other caring responsibilities, and they are likely to have practical questions (Box 3). Ensure contact details are up to date, identify who should be contacted if there is a sudden change, and if they want to be contacted in the middle of the night, and clearly document this in the notes. Ascertain any specific religious or cultural practices that need to be observed. For example, in the Jewish faith burial traditionally takes place within 24 hours of death. A question that might be asked is: “Are there any particular arrangements or instructions that you or your relative would want followed?”¹²

Emotional support starts with providing clear, honest information. Careful documentation of conversations helps to ensure consistency and reduce confusion. Make time for family meetings and allow relatives space and time to ask questions. Encourage relatives to express their feelings; acknowledge their loss, and listen to their concerns. Avoid platitudes, and recognise that silence might be appropriate when sitting with a grieving relative.

What you need to know

Effective support can make a considerable difference to the relatives of people who are dying; helping to allay fears, reducing stress and anxiety, and minimising suffering in bereavement.

Clear communication around practical considerations (death certificate, funeral arrangements, information around autopsy, etc) and psychosocial support (normalising grief, cultural and spiritual considerations) is key.

Doctors need to familiarise themselves with local systems and protocols. Written communication in addition to verbal is beneficial.

Box 1: Consent, capacity, and confidentiality*Consent*

Consent must be given voluntarily, by an appropriately informed person who has capacity. Consent cannot be given on behalf of others except

if the patient is a child under 16,

someone is authorised to give consent under a lasting power of attorney,

someone has the authority to make treatment decisions as a court appointed deputy.⁴

Capacity

A person who lacks capacity is unable to make a decision for themselves because of an impairment or disturbance in the functioning of their mind or brain (The Mental Capacity Act 2005, UK). At the end of life, capacity can be impaired by sedation, analgesics, renal failure, delirium, etc, and should always be carefully assessed.

Confidentiality

Under common law, without consent patient information can only be disclosed if

there is an overriding public interest, or

the law requires it.

The duty of confidentiality extends beyond death (General Medical Council Guidance, UK).⁵ In cases where there are no clear instructions from the patient before death, take into account

Will disclosure of the information cause distress or be of benefit to the patient's family?

Whether the disclosure will also disclose information about anyone else

Is the information public knowledge?

What is the purpose of the disclosure?

Box 2: Risk factors associated with complicated grief⁸*Background factors*

Close relationship

Being female (especially bereaved mothers)

Minority ethnic status

Insecure attachment style (difficulty forming stable interpersonal relationships)

High level of pre-death marital dependence

Treatment related factors

Aggressive medical interventions (eg, ITU, ventilation)

Ambivalence regarding treatment (of patient or relative)

Family conflict

Economic hardship

Caregiver burden

Death related factors

Multiple losses

Low acceptance of death

Violent death

Finding or viewing the loved one's body after a violent death

Death in hospital (rather than home)

Dissatisfaction with death certification and/or notification

Discuss the process of dying

If appropriate, explain that most people who die experience a gradual deterioration in conscious level, will eat less, drink less, and spend more time asleep. It is often difficult to say how long this process will take and relatives might find this uncertainty difficult. "How long have they got?" is a commonly asked question. Answering in terms of "days," "weeks," or "months" is a way of providing an estimate of prognosis while

acknowledging the uncertainty. Sensitive address relatives' anxieties, for example around pain or medication. You could ask: "Is there anything you are particularly worried about?"

Offer chaplaincy support irrespective of the presence or absence of any religious affiliation; this can be useful for people struggling with existential issues around life and death. Specialist palliative care teams can provide social work support around issues such as finances, complex caring responsibilities, and residency.

Box 3: Practical questions that relatives might ask

Must visiting hours be adhered to?
 Are relatives able to stay overnight?
 Are children allowed on the ward?
 Does the hospital provide any support with car parking?
 Where are the prayer rooms?
 Is there a chaplain or other spiritual leader at the hospital who can provide support?
 Are there any facilities to make meals or hot drinks?
 Who can relatives talk to if they have questions?
 Which is the best number to call for an update on the patient's condition?

Ascertain whether there are any children who will be affected by the patient's death. Children benefit from knowing what is happening and getting the opportunity to visit and say good bye.¹³

Ensuring dignity for patient and relatives

There is guidance on the management of a dying patient,¹⁴ and in general terms ensuring their comfort is likely to result in a better experience for relatives. Separating care of the dying patient from care of their relative is an artificial distinction. Making clear to relatives how and why particular medications or management strategies are used at the end of life can help; talking about general management strategies rather than discussing details can also help in situations where confidentiality is problematic. Relatives often ask about the physical measures being taken to ensure comfort. Explain that common symptoms such as breathlessness, pain, and agitation will be regularly reviewed and treated appropriately. Describing how these medications will be administered can be helpful, particularly if the patient cannot swallow. Syringe drivers are frequently used at the end of life and explaining that these ensure reliable and safe delivery of medication without the need for intravenous access can reassure relatives. Concerns around opioids are common — for example, that they will cause death, or that they lead to addiction and tolerance. There is no evidence that appropriate doses of opioids shorten life.¹⁵

Encourage relatives to speak up to nursing staff if they see pain or distress in the patient to enable prompt management of symptoms. For patients who are unable to drink, relatives can help with mouth care. Consider moving patients to a side room. Consider relaxation of infection control measures so relatives can, for example, lie on the patient's bed with them and hold hands.

Providing supportive care to relatives after death

Following death, the patient's body is prepared in a procedure known as "last offices" or "laying out." Historically carried out by family members (and still the preference in some religions, for example Islam), in hospitals this is now commonly performed by nursing and healthcare staff. During this procedure, the body is washed, limbs are straightened, and jewellery and mechanical devices such as syringe drivers are removed. Relatives should be offered time to spend with the patient's body. Advise or warn relatives that they might find the patient's appearance upsetting.

Afterwards, the body is transferred to the mortuary. It will be possible to view the body in the mortuary. Death certification should occur as soon as possible. Relatives will need to visit the bereavement office to collect the death certificate, before they are able to register the death. If the coroner needs to be

informed, discuss the reasons with the family and explain that this could lead to a delay in issuing the death certificate. This process is different in a community setting.¹⁶

Providing written information about bereavement can be helpful for relatives (Box 4). Advise relatives where they can find support, and provide information about local services.

Post-bereavement follow-up is variable. Studies have shown that sending a letter of condolence to bereaved relatives and offering the opportunity of a meeting with the clinical team can help reduce severe grief reactions.¹⁷

After a patient's death, inform their primary care provider of the death, including relevant details such as the cause of death and any other notable circumstances such as whether a post mortem is necessary. Where relatives are registered with the same general practitioner, this can help ensure bereavement support in the community.

Caring for dying patients can be stressful, and doctors might also benefit from support. Such support varies, and includes Schwartz Rounds (Box 5), chaplaincy, and employee wellness programmes.

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A daughter's view, by Jane Harris

Last year my mum was admitted to hospital with organ failure and I immediately travelled to Scotland to be with her (fig 1¹, fig 2²). This was my first experience of witnessing someone die and I was, and still am, scared by the experience. I felt ill equipped to know what to do and found that observing her gasping for air and in a state of panic whilst in and out of consciousness was terrifying. I desperately wanted her pain relief to be increased, and while I waited and waited for permission to be granted by a senior staff member, I sat with mum feeling helpless and alone and afraid.

Looking back, the most helpful intervention came via a cleaner who was tidying up the room and who smiled and made eye contact with me. She said, "Just keep talking to your mum ... that will soothe her ... she can probably still hear you, you know."

Eventually permission was given to up her pain relief. She became calm and died later that day.

I am left with anxious feelings and sadness about her last hours.

It might have helped if someone had explained to me what to expect in the final stages of mum's life. Waiting and waiting for permission from a senior staff member seemed to me to be inappropriate and bureaucratic.

I felt as if I was causing problems by insisting that mum have more pain relief. It felt like a battle ground rather than a place of care.

What I wanted was to be part of a team tending to my mum's final chapter. I wanted mum to have joined up person (family) centred care, of which I could play a part.

By not having this experience I felt alone, frightened, and most importantly powerless.

Box 4: Resources for relatives and caregivers following the death of a patient

Cruse is a bereavement support charity that offers information, online/phone support, and events. It covers bereavement in children and different faith groups. <http://www.cruse.org.uk>

The Compassionate Friends is a charity that offers support to bereaved parents and family who have suffered the death of a child or children regardless of their age or the cause of death. <https://www.tcf.org.uk/content/for-the-bereaved>

Say Their Name is a promotional film made for TCF by Jane Harris and Jimmy Edmonds <https://www.tcf.org.uk/>

Much Loved is a website that brings together different bereavement support organisations. Its aim is to help those affected by grief to find the most relevant contact details from the many support agencies in the UK <http://www.muchloved.com/gateway/grief-support-organisations.htm>

Both Macmillan and Marie Curie offer useful information regarding grief and how it can affect people <http://www.macmillan.org.uk/information-and-support/coping/at-the-end-of-life/after-death/bereavement.html> <https://www.mariecurie.org.uk/help/bereaved-family-friends/dealing-grief/bereavement-or-grief-counselling>

Winston's wish www.winstonswish.org provides information to professionals, family members, and children on supporting children when they are bereaved.

The Royal College of Psychiatrists has a useful leaflet for anyone who has been bereaved. <http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/bereavement.aspx>

Beyond Goodbye is a resource for all those who have been bereaved, in particular by a sudden or untimely death. <http://beyondgoodbye.co.uk>

The Good Grief Project is a new initiative from Jane Harris and James Edmonds with a mission to encourage creative responses to grief and to help the bereaved find expression through various art forms and media <http://thegoodgriefproject.co.uk/>

Exploring Grief with Photography is artistic and therapeutic responses to grief by Jane Harris and James Edmonds <http://www.tandfonline.com/doi/full/10.1080/02682621.2015.1064583>

Box 5: Schwartz Rounds¹⁸

Schwartz Rounds provide a structured forum allowing staff, both clinical and non-clinical, to come together to discuss the emotional and social aspects of working in healthcare.

The purpose of Schwartz Rounds is not to try to solve problems or discuss clinical aspects of care; rather to understand the challenges and rewards that are intrinsic to providing care.

There is some evidence that Schwartz Rounds can help staff feel more supported in their jobs, less stressed, and gives them increased insight and appreciation for each other's roles. Schwartz Rounds can also help to reduce hierarchies between staff and to focus attention on relational aspects of care.

The underlying premise for Schwartz Rounds is that the compassion shown by staff can make all the difference to a patient's experience of care, but that in order to provide compassionate care staff must, in turn, feel supported in their work.

Education into practice

Think about the last time you were involved in the care for someone who died. Has this article given you ideas on how or what words you might use to support relatives better?

Does your ward, unit, or department have bereavement support material? Do you know where it is? Do your colleagues?

Are you familiar with the different cultural practices surrounding death of the different peoples in your community, including treatment of a body and funeral ceremony arrangements? Do you know how to access information about this?

Does your trust collect post-bereavement feedback from relatives? Has anyone analysed the feedback relevant to your department? What did it show?

Patient involvement

This article was co-written with Jane Harris, a bereaved mother and daughter. In addition to writing the testimonial, Jane shaped the content of the article.

18 The Point of Care Foundation. About Schwartz Rounds. <https://www.pointofcarefoundation.org.uk/our-work/schwartz-rounds/about-schwartz-rounds/>

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Figures



Fig 1 Saying goodbye. Jane and her daughter, Rosa, at her mother, Patricia's bedside

